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ABSTRACT

Home based respite care for severely retarded and severely disabled persons was evaluated through questionnaires completed by 91 respite care units over a six month period. Ratings of clients' level of disability were compared to those of clients served in the same region in previous years. Disability levels of clients denied services by the pilot project were analyzed, and ratings of families and providers were examined. Results indicated that significantly more multiply handicapped clients were served; there was overwhelming satisfaction by parents of the level of services received; and that providers felt they were able to meet client needs well. It is concluded that the flexibility, low cost and correlation with family preferences support the worth of home based respite care. (CL)

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HOME-BASED RESPITE CARE FOR THE SEVERELY RETARDED

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Home-Based Respite Care for the Severely Retarded[1]

Respite care, the provision of temporary daytime or overnight relief services to families caring for developmentally disabled persons at home, is a growing program concept in the community-based services movement in the field of mental retardation. (Paige, 1977) A variety of program models have been created to meet this need for relief services, ranging from informal "baby-sitting" arrangements for several hours of care, to three or four week residential care in an institutional setting. A 1978 report of the Massachusetts Developmental Disabilities Council (Upshur, 1978) found, however, that the range of possible models of respite care is not equally available and that certain of the less formal models tend to exclude severely retarded and disabled persons from services.

The lack of alternatives for families with the most severely involved clients is of major concern since clearly they need as much, if not more, relief than other families due to the intensity of the clients' needs. In addition, despite the more complex needs of severely retarded and disabled clients, most families reported in the 1978 study that they preferred respite care,

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whether daytime or overnight, to take place in their own home. (Upshur, 1978) This combination of issues and concerns led the Massachusetts Developmental Disabilities Council to fund a pilot project to demonstrate the feasibility of providing home-based respite care for the most severely retarded and disabled clients in one region of the state. The evaluation of the project was designed to assess the ability of the pilot project to serve severely retarded and disabled clients, to measure client family satisfaction, and to determine actual versus perceived levels of specialization needed to provide home-based care for this population.

THE PILOT PROJECT

The pilot project was initiated in a suburban region of the state as a cooperative venture of several local, previously operating, home-based respite care programs funded by the Department of Mental Health. A project director supervised the recruitment of twenty community persons who were provided 60 hours of training on developmental disabilities, treatment methods, patients' rights, control of behavior problems, and the procedures involved in feeding and physical adaptive equipment. Publicity about the project was made available through local Associations for Retarded Citizens and similar interest groups as well as community newspapers, public schools, and existing respite care programs. Fees

for the service were either partially or fully provided by the project grant. Families needing respite care were encouraged to call the project offices and submit information for an application for care. Arrangements were then made for one of the twenty trained community providers to go to the client's home or to be available in the provider's own home to administer daytime, evening or overnight care. Providers were paid on an hourly or daily basis (for overnight care), for actual care delivered, and were also paid for the time they participated in training. On-call emergency back up services were available to the providers in the event of a crisis. Medical liability insurance was purchased to protect the project and each provider in the event of an injury to a client.

METHODS

Four major approaches were taken to evaluate the success of the project in serving severely retarded and disabled clients.

1) Ratings of the level of disability of clients served in the pilot project over a period of six months compared to the level of disability of clients served in previous years in the same region in home-based respite care.

2) Ratings of the level of disability of clients denied services by the pilot project and analysis of the reasons for denial.

3) Family satisfaction ratings.

4) Provider ratings of the type of training required to provide services to this population.

A simple rating scale of level of disability was devised to collect data on respite care in this region of the state prior to the implementation of the pilot project. This rating scale was continued in use so that the historical data could be utilized for comparison purposes. The scale asked for the primary and accompanying disabilities to be classified as follows: Mild, Moderate, Severe, or Profound. The scale was completed by a project staff person who had received the parents' request for respite care. The data was maintained for evaluative purposes even if the pilot project denied, or for other reasons did not provide, services to the client.

The family satisfaction rating scale asked five questions of the family concerning: 1) general satisfaction with the respite services delivered; 2) satisfaction with the provider's following of instructions; 3) satisfaction with the provider meeting medical, behavioral and developmental needs of the client; 4) satisfaction with the level of training of the provider; and 5) the willingness to recommend the provider to other families. The scale was mailed directly to the family by the project office with a stamped return envelope. Families received the scale after respite care services were completed and the families were granted anonymity.

The provider feedback consisted of a questionnaire with fifteen items, (both ratings and open-ended questions), covering

how well the provider him/herself felt the respite care situation had been handled, and whether or not the training received helped them specifically in caring for each client served. Providers were mailed a questionnaire each time they provided service, and were required to return the completed form before payment was made to them for the services performed.

RESULTS

The results will be discussed in three major sections addressing the primary questions of the evaluation:

I. Ratings of disability level.

II. Family satisfaction.

III. Provider ratings of need for training.

I. Ratings of disability level.

During the six months of data collection, a total of 91 different respite care units were provided by the pilot project. Some of these units represented two or more different periods of service for the same client and others represented respite care in a group situation (i.e., a community provider relieved the houseparent in a community residence.) For purposes of this research, only respite care provided for an individual client was tabulated and the data from multiple respite care units provided to the same client were excluded after the initial unit of care.

In addition, for some clients, complete files were not maintained. This resulted in disability data being available on 27 individual clients from the pilot project. Of these 27 clients, 16 (59.2%) had mental retardation indicated as the primary disability, and 9 were severely or profoundly retarded. Other primary disabilities included were cerebral palsy, epilepsy, autism or special medical problems. Over 77% (21 clients) were multiply handicapped. The median age of the clients was 13 years, and the range was from 2 to 52 years of age.

Data was reviewed on 160 respite care units provided in the two preceeding fiscal years (1977-78 and 1978-79) by four on-going home-based respite care programs in the region. Each of the four had at least one year of complete data available for analysis. A chi square was performed to test the null hypothesis that the on-going programs and the pilot program were serving essentially the same levels of disability (i.e., no difference between the two groups). A chi square of 2.18 (df = 3) was obtained showing no significant difference between the two groups on the level of primary disability. However, when the difference between the two groups in the proportion of multiply handicapped clients is compared, a Z of 6.49, significant beyond the .001 level, is obtained. Thus, while the pilot project served clients with similar levels of primary disability, it appears to have served a significantly greater proportion of multiply handicapped clients. (See Table 1)

Table 1 about here.

Profiles of 16 clients requesting but not receiving services were also analyzed. These clients were found to be significantly less multiply handicapped than the clients served by the pilot project ($Z = 2.66$, $p > .01$). A chi square test of the difference in disability level was not significant. Thus, clients not provided services by the project appeared to be similar in level of primary disability to those served, but were significantly less multiply handicapped.

The reasons for care not being provided varied with the most common reason being that no provider was available for the particular time requested (6 clients, or 37.5% of the total). Other variations of scheduling problems including the client family changing their plans, the scheduled provider having a family emergency, etc., account for four other case. of no service being provided. For three cases, no reason was recorded as to why service was not provided. However, in only two cases of behaviorally difficult clients (one a fire-setter, one sexually abusive) was the client's disability given as the reason for not providing care.

II. Family satisfaction

Family response to the quality of respite care services pro-

vided was available from 23 families of 35 families served (65.7%). When multiple respite care services had been provided to a family by the same provider, only the initial family response scale was included for analysis. Analysis of incomplete records was done to see whether or not other information would point to a pattern of families of more disabled clients not responding. While some of the non-responding families could have been dissatisfied with the type of service received, a check of the disability level of those clients whose families did not return feedback forms does not show a significantly different pattern of disability level (chi square = .18, df = 3). Conclusions drawn from the questionnaires that were returned thus should be representative of all services provided. The results of the family ratings can be found in Table 2.

Table 2 about here.

It can be seen that, at most, two families were very unhappy with the care received. While some families did differentiate among the top three ratings to some extent, particularly on questions #1 and #4, it is clear that there was overwhelming satisfaction with the level of services received. In terms of problems mentioned by families with the quality of care, only one family reiterated that their particular provider needed more training. One family would have preferred a male provider for a 31-year-old

male client. Other comments stated that the only problem was that there was not enough respite care available. As far as recommendations, families noted only that they would like more care available, although the same family critical of the level of training of their provider stated again that more training should be provided.

When questioned as to the difference between the pilot project's services and that of other services, only four families made comments, but all were positive. Two noted that the previous providers were less well-trained. One family noted that they had never had overnight care available before. The fourth family noted that they never had care available in their own home before. These comments combined with the strongly positive ratings on all other questions point to strong family satisfaction with the services provided.

III. Provider ratings of need for training.

Provider ratings as to the types of skills required to adequately serve the severely retarded or disabled client in a home setting were obtained from 39 different respite situations. (NOTE: While only 35 individual families were served during the data collection period, some families were served by more than one provider at different times; multiple ratings by the same provider of the same client were not included for analysis, however; only the rating obtained after the initial unit of service was included.) Table 3 summarizes the results of the provider responses.

Table 3 about here.

It can be seen from the ratings that, in terms of ability to serve the clients adequately (Questions #2-5), there was clear consensus on the part of the providers that they were able to meet client needs well. The issue of whether or not they had adequate information about the client (Question #1) is more clouded and appears to relate somewhat to administrative issues as to how and when information was obtained from the families. However, comments also indicated that families simply overlooked or forgot to provide some information on habits, favorite activities, or some aspects of behavior. No information of major importance was lacking.

Questions on the usefulness of the training received provide a less clear picture, although almost three-quarters of the responses do indicate moderate to strong feelings about the usefulness (73.3% rate Question #7 at '4' or more). On the other hand, over 30% of the respondents felt that even more training was needed for their particular clients, and another third (on Question #9) felt that they could have provided the same quality of service to the particular client without <u>any</u> training.

Provider comments on particular areas of training that were especially useful, and other topics that they would have liked training for in order to be more useful to the particular clients served, are also important. Topic areas commented upon as being

particularly useful (6 comments altogether) were: behavior management (4 comments) and seizures (2 comments). Topic areas where more training was requested (15 comments) included: non-verbal communication and signing (5 comments); autism (2); activities to do with clients (2); more behavior management (1) feeding (1); therapies (1); how to help non-mobile client up stairs (1); spina bifida (1); how to prepare provider home for a client (1). General recommendations given at the end of the questionnaire by providers included a request for more physical and occupational therapy training; orientation for families as to what information to give to providers, and discussion of their role vis á vis the provider's role; more hands-on training; a recreational center where clients could be taken for activities; and a comment that 9 days of continuous respite care for a difficult client is too much for one provider.

DISCUSSION

It can be seen from the above results that, although the disability level of clients served by the pilot project did not change substantially from the disability level of clients served in the on-going, home-based respite care programs, significantly more multiply handicapped clients were served. While it may be difficult to conclude without more refined ratings of disability that, simply based on the fact of multiple handicaps, a client is more difficult to serve, it seems clear that the pilot project has reached quite disabled clients and demonstrated that they can be served success-

fully in a home setting with trained community providers. The conclusion that success has been achieved is based on a variety of factors: 91% family satisfaction with services; no incidents of behavioral or medical crises over a period of six months and 91 respite care units; denial of services to only two clients for reasons based on their disability.

The characteristics of the clients denied services are worthy of note. Both had severe behavioral problems in addition to other handicaps, and the reason they were not served had to do with risk of injury to other family members of the provider rather than lack of willingness of the providers to give service. In both cases, the client family wanted out-of-home respite care (i.e., they did not want to have to leave their own home and have the provider come in to give respite services). Providers, however, were unwilling to risk a fire in their own home or apartment (in one case), and in the other case, providers with other children were unwilling to risk possible abuse to their children at the hands of the client. Providing respite care for such behaviorally difficult clients may require an institutional setting. However, an innovative suggestion arising from this experience is to have a home purchased for the purpose of providing out-of-home respite to just such clients. Rather than operate the respite home on an institutional staffing pattern, however, the home would be utilized only when needed, and the staff would consist of a community provider who would live in

with the client for the duration of the respite care unit. Such a model would be clearly more cost-effective than institutional care for such clients, but would also meet parent concerns about having their family members in home-based settings.

The scheduling problems of this model of care are difficult to solve as long as the providers are paid only for care delivered and are allowed the option to work when it fits their own family schedule. Of course, the use of community providers who work only part-time makes this model the most cost-effective model of respite care. But the addition of a stipend for on-call duty might make this model of care more flexible and available.

The level of training provided by the pilot project seemed very necessary in caring for some clients, but totally unnecessary when caring for others. Recommendations as to how much training is required to deliver home-based care to this severely retarded and disabled population are thus unclear. It should be assumed, however, that even if not entirely related to each client's situation, the provision of extensive training is a required protection for delivering respite care through use of community providers. At the very least, it allows adequate time for staff to observe the providers and to anticipate those who may not work out. It also allows providers to make a clear decision as to whether or not they feel they can deliver such individualized care.

In summary, the provision of respite care services by community providers in their own homes or homes of clients is a model of

respite services preferred by a number of families with severely retarded and disabled members at home. This pilot project has successfully demonstrated that the most severely handicapped persons can be adequately cared for in a home-based situation on a temporary basis by a trained community provider. While the needs of some behaviorally difficult clients may still not be met through home-based care, the flexibility, low cost and fit with family preferences strongly indicate that this model of respite care should be expanded to serve clients of all disability levels.

References

1. Paige, M., Respite Care for the Retarded, U.S. Department of Health, Education and Welfare, Social and Rehabilitation Services Administration, Division of Mental Retardation, 1977.

2. Upshur, C., Final Report of the Respite Care Policy Development Project, Provider's Management, Inc., Boston, Mass., 1978.

Table 1

Disability Levels of Clients Served by the Pilot Project and Clients Served in Other Programs

Level of Disability	Clients Served by Pilot Project (N = 27)		Clients Served by Other Programs (N = 160)	
	No.	Percent	No.	Percent
Mild	4	14.8	28	17.5
Moderate	7	25.9	58	36.3
Severe	10	37.0	39	24.4
Profound	6	22.2*	35*	21.9*
Multiply Handicapped	21	77.8**	31	19.4**

* Chi square = 2.18 (df = 3), N.S.

** Z = 6.49, p > .001

Table 2

Ratings of 23 Families in Response to Questions On the Quality of Respite Care Provided

Question	Percent Responding			
	1 or 2 Strongly Disagree	3 or 4	5 or 6 Strongly Agree	No response
1. I am very satisfied with the type of care received.	8.7	8.7	82.6	--
2. My instructions were followed very well.	--	--	91.3	8.7
3. The care my family member received was appropriate for his/her needs:				
medically	8.7	--	82.6	8.7
behaviorally	4.3	--	82.6	13.0
developmentally	8.7	--	69.6	21.7
4. I feel the provider was well trained	4.3	8.7	87.0	--
5. I recommend this provider to other families of the developmentally disabled.	8.7	--	91.2	--

Table 3

Provider Ratings of 39 Different Respite Care Service Units

Question	1 or 2 Strongly Disagree	3 or 4	5 or 6 Strongly Agree	No response Not applicab
1. Did you have adequate information to serve client?	5.2	7.7	87.1	--
2. Were you able to meet client's daily living skills?	--	5.1	92.2	2.6
3. Were you able to feed client without difficulty?	--	5.1	38.4	56.4
4. Were you able to use client's physical/adaptive equipment without difficulty?	--	--	25.7	74.3
5. Were you able to deal with medical problems/emergency without difficulty?	2.6	--	12.8	84.6
6. Were you able to recognize the client was becoming difficult?	--	2.6	23.0	74.3
7. Was the special training received useful?	10.2	25.6	61.5	2.6
8. Could you have used more training?	53.8	10.2	28.1	7.6
9. I could (not) have done as well without training.*	23.1	20.4	30.7	25.6

* For purposes of comparison, the ratings were inverted since the wording of this question made the higher rating the less desirable response.